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*Testimony before the Appropriations & Human Services Committees:*

Submitted By: Julia Wilcox, Senior Public Policy Specialist, CT Nonprofits

Public Hearing Date: March 28, 2014

*Commentary, Concerns and Recommendations Regarding:*

1915(c) Home and Community-Based Services Waiver:  
CT Acquired Brain Injury Waiver II Application

Good Afternoon, Senators Bye and Slossberg, Representatives Walker and Abercrombie and distinguished members of the Appropriations and Human Services Committees. I appreciate the opportunity to provide testimony regarding DSS' proposed CT Acquired Brain Injury Waiver II. My name is Julia Wilcox, Senior Public Policy Specialist for the Connecticut Association of Nonprofits (CT Nonprofits.) CT Nonprofits is a membership organization that represents more than 525 mission-based, nonprofit agencies. Approximately 300 of our member organizations contract with state government for a variety of human and social services. The following testimony is presented on behalf of the Acquired Brain Injury Forum of CT Nonprofits, representing service provision to the majority of individuals on the existing ABI Waiver I.

First and foremost – As this hearing convenes the day following release of the Appropriations Committee's Midterm Budget Adjustments, CT Nonprofits applauds the Legislature for the increase of \$650,000 in FY15 (from the Medicaid account in the DSS budget), to reduce the ABI Waiver Waitlist. Your demonstrated support is greatly appreciated!

*'People with disabilities constitute the nation's largest minority group,  
and the only group any of us can join at any time.'*

This is most clearly illustrated by the particular population that is represented here today – survivors of an acquired brain injury, who have had their very existence altered in a heartbeat. Relative to other sub-sectors in the field of disabilities, this particular group of individuals has struggled not only for services, but for understanding and recognition of their very complex and individualized needs. The groundswell of both visibility and acknowledgement of their issues in less than one year's time is a tribute to the very passionate self-advocates, family members and supporters that you see before you today.

Nonprofit Providers of ABI Services stand in complete support of any process which will enhance opportunities for brain injury survivors to receive the services that they so richly deserve, and enhance their quality of life. With that said, while CT Nonprofits supports the concepts presented in the proposed Waiver II, we must respectfully withhold support, in the absence of further clarification related to the ultimate implementation, regulation and fiscal process.

Please Note: The Brain Injury Alliance of Connecticut is a member of CT Nonprofits and while we do not have consensus with their position in support of the Waiver II Application, we are in agreement with the concerns and challenges they presented. In addition – we concur with BIAC that:

*'Under no circumstances should any individual currently receiving services under ABI Medicaid Waiver I be forced into institutionalization because of the inability to meet his or her needs.'*

CT Nonprofits' reservations related to the Acquired Brain Injury (ABI) Waiver II are largely born out of frustration related to issues with the regulations, implementation and funding structure associated with the existing Waiver I. With all due respect to the Department of Social Services (DSS), there has been an ongoing lack of clarity and communication with all stakeholders that makes support of an additional Waiver option extremely difficult.

Since 1999, DSS has overseen the Medicaid ABI Waiver in Connecticut, serving brain injury survivors across the state. The ABI Waiver provides essential services to allow individuals with brain injuries to live successful and independent lives in their communities. Connecticut nonprofits have played a vital role in providing these essential services to a majority of individuals on the ABI Waiver. DSS has now proposed the addition of an ABI Waiver II which has been proposed to: "serve more consumers" with brain injuries in Connecticut and "add additional services." However, due to the new funding structure being proposed, the ABI Waiver II will not be a viable option for nonprofits. If the ABI Waiver II is approved as written, it will be incredibly difficult for nonprofit providers to serve brain injury survivors under the new reimbursement rate configurations.

Based on the current ABI Waiver funding, which has essentially remained flat since the program's inception, nonprofit providers already struggle to hire and maintain competent and educated employees. The ABI Waiver II proposes to decrease Independent Living Skills Services and replace it with a less skilled position of Recovery Assistant, while reducing the reimbursement rate by 40%. This reduction will make it nearly impossible for providers to hire and retain employees who are qualified to meet the complicated and challenging service needs of this population. It will also make it nearly impossible for providers to meet expenditures and places nonprofit ABI Providers at risk of having to abandon this essential program or face financial hardship. In the end, if nonprofits cannot fulfill their Mission it is the survivors who are truly being placed at risk.

Nonprofits are vital to Connecticut's economy. They work with the state to provide quality services efficiently and cost effectively. They assist residents who have disabilities to achieve their independence, participate more fully within the community and often become tax-paying employees. The nonprofit sector employs tens of thousands of Connecticut residents and pay payroll taxes. Nonprofits strive to maintain employee benefits even though these costs continue to increase while reimbursement rates stay constant. If the ABI Waiver II application is approved as written, nonprofit providers will be faced with heartbreaking decisions to reduce wages, eliminate benefits and/or ultimately reduce or eliminate service delivery to brain injury survivors. This is completely unacceptable and not in any way a reflection of the desired outcome of this dedicated network of service providers.

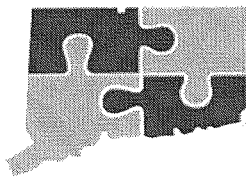
In closing, CT Nonprofits supports the Committees and the Department of Social Services, in their efforts to continually improve upon the delivery of services and assuring the highest standards in terms of both quality of care and accountability. We welcome the opportunity to serve as a resource as the State moves forward to enhance services provided to Acquired Brain Injury Survivors, their families and further support the remarkable network of service providers who are intensely committed to the individuals they serve.

*(Please refer to 'Overview of Concerns' pages 3-5, for additional insight.)*

I thank you for your time and consideration of these critically important issues. As always, please do not hesitate to contact me at any time, with questions, or for additional information:

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### CT Nonprofits' Overview of Concerns – ABI Waiver II:

#### **1. Communication:**

A particular concern related to the introduction of a new ABI Waiver, is the lack of communication the Provider community experiences with DSS regarding the current Waiver. When seeking clarification regarding regulations, it is very difficult to find consistency across the state as there is no updated written or electronic resource available to consult. The Provider's Council has offered feedback, participated in committees with the DSS designated representative, and even worked on handbooks which have unfortunately, never come to fruition. If ABI waiver II is approved, providers are very concerned that they will have little support from DSS to navigate the new waiver.

An additional communication challenge has been with regards to the 4.43 formula error changes. This is in regard to the formula DSS (along with Allied as the fiscal intermediary) have automated for calculating reimbursement rates. The providers were promised that all service plans would be revised to utilize a 4.43 formula (the previous 4.33 formula caused multitudes of services provided to survivors that was not reimbursable) by October of 2013. As of today (March 2014), more than six months later, as a group we estimate only 5% of plans have been corrected.

#### **2. Regulations that were introduced in March 2013**

On March 26, 2013, regulations were proposed regarding ABI waiver I. A follow up letter with commentary was submitted by CT Nonprofits to DSS on the behalf of several agencies who serve a majority of the participants on the ABI Waiver. There were several areas that were found to be problematic in the proposed regulations including the vague requirement for data and the additional vague requirement of signatures of participants. When a response was received in October 2013 (7 months later!), DSS acknowledged in the letter that there was no detailed reporting structure and providers will be notified when it was developed. Additionally the letter from DSS stated that there are provisions of the proposed regulation that are still being developed; once the Department has had an opportunity to specify such details, providers will be notified and be given a reasonable amount of time to comply with these requirements.

This is another example of the unfortunate, ongoing lack of communication between DSS, the provider community and those that we are all here to serve. New regulations were posted in a law journal which is not typically accessible to most, and there was no communication from DSS directly to providers. There are still many outstanding questions from providers about how and/or when to comply with these regulations.

#### **3. Service Plan revisions p26, p81, p86**

Example, as reported by one of the major ABI Provider agencies: 'Currently 66% of the individuals we serve have expired service plans. After polling additional service providers, it has been established this percentage is for the most part consistent across agencies, meaning that more than half of all individuals with brain injuries on the waiver are being served with expired service plans. For another agency, their longest expired service plan expired in February of 2008, with several others that expired in 2010. This means that there are individuals that have not had updated plans in six years. This is a problem as goals have not been updated and plans have not been assessed to determine if they support the individual's current needs. In this situation, this has been brought to DSS' attention via monthly emails from an organization since January 2013,

and less regularly before that date. Providers question how DSS may accurately assess the cost neutrality of the ABI waiver I without knowing that services plans are matched to the participants needs.'

The application states in ABI Waiver II that there is an automated case management system capable of conducting queries to ensure service plan reviews are happening in a timely manner as well as supervision meetings that monitors the progress on plan of care reviews. As stated, this has not been the experience of Providers with ABI waiver I and they would logically assume this will be the case for ABI waiver II.

Plans are currently being changed by the DSS social worker, sometimes with, sometimes without the input of the team. Teams constantly have to fight to maintain the appropriate level of services and keep plans from being cut. There is no formal assessment process to determine which changes need to be made to the plan and the social workers are not doing this consistently across the state. Often times the plans are changed retrospectively, causing agencies to provide services for months that they are not able to be reimbursed for. Along with the costly formula error mentioned above, this has great financial consequences for the providers due to administrative issues with plan processing at DSS. This has been communicated to DSS many times but there has been no improvement.

#### **4. Rate issues**

For ABI waiver I there has been one rate increase in the last 17 years. Each year an agency has to absorb increased expenses due to basic inflation and cost of operation. There are also additional administrative expenses associated with all regulation changes that DSS implements. In an effort to retain quality staff, we choose to give our staff merit increases every year as well as vacation time and quality benefits but doing so gravely impacts our financial solvency. The survivors as well as the men and women who are ILSTs, companions and job coaches are the backbone of this waiver, and deserve to receive wages that are commensurate with their experience. Should providers expect rate increases in ABI Waiver II? Will ABI Waiver I ever receive a rate increase?

#### **5. Cost Cap**

Since the inception of ABI waiver I, agencies and private providers have worked diligently to assist their brave survivors in the transition back into community life after the devastating impact of brain injury. The reduction in the cost cap by 50% will result in the loss of access to home-based services by many survivors across the state. These individuals will lose the opportunity and dignity of an independent life in the community. This would be a loss for far too many.

#### **6. Satisfaction survey p109**

Although it states that satisfaction surveys are administered to survivors and providers, there have been none in recent history.

#### **7. Reportable incidents p101**

The ABI waiver application II references a reportable incident structure that includes a form as well as an individual to contact at DSS but it does not specify who the contact is or how to obtain the form. At the most recent meeting of CT Nonprofits' ABI Forum, providers were unaware of this. Additionally after much search of the DSS website we have not been able to find any such form or individual to contact.

#### **8. Unclear language in application**

ABI waiver II application vaguely refers to training requirements but gives no specifics about curriculum, who will provide the training and at what frequency? This makes it very difficult to anticipate cost, time and knowledge needed by staff to fulfill the requirement.

The waiver application also refers to CARF requirements. Although providers have been told by the DSS Representative that there would be no CARF requirement for providers, they are still referenced.

Additionally, the CARF requirement that they refer to in the application is the wrong accreditation requirement, as most individuals on the waiver are not in a hospital or medical setting.

In Summary, we respectfully request that the Legislature and DSS address the problems in ABI Waiver I before transferring these issues to a second ABI Waiver

It is evident that there are many issues with the administration of ABI waiver I. Service plans are continually expired, there have not been adequate rate increases, regulations are imposed without being clear or communicated well, satisfaction surveys are not being administered, there is no clear system for reportable incidents, and most of all, communication from DSS to both survivors and providers is insufficient.

With the potential for moving toward ABI waiver II, there is still much that is unclear. The language in the application leaves many questions about training and CARF requirements and it is concerning that many brain injury survivors may not have the opportunity to live independent lives in the community due to the lowered cost cap.

Moreover, the application from ABI waiver I had several mechanisms in place such as an annual plan review, satisfaction surveys, CARF requirements, requiring input from survivors as well as a representative attending providers council meetings. When that waiver application was approved, it was done so with the expectation that what was written into the application would become practice. It never happened. We are now at the juncture of potentially starting a new waiver without resolving any of the existing issues and concerns. These must be addressed before the nonprofit provider network can support the creation of a new waiver.

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I thank you for your time and consideration of these critically important issues. As always, please do not hesitate to contact me at any time, with questions, or for additional information:

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